

Senators and Representatives.

My name is Tim Lamb I was born in New Haven, grew up in Hamden and Cheshire and have lived in Glastonbury for the past 25 years.

I believe I'm more open and objective than most when it comes to the "Lyme Disease" and "Tick Borne Diseases" controversy as I've never had Lyme or Tick Borne Diseases. However, I and my family have experienced the controversy first hand as our daughter was bitten by a tick and subsequently came down with Lyme and at least one other tick borne disease, Babesiosis.

Like any normal parent when our daughter was first bitten and then when symptoms started we had our daughter treated with what we thought was the best care possible, from our daughters pediatrician group to the top pediatric infectious disease specialist at Hartford Children's Hospital as well as a pediatric expert at Boston Children's Hospital. Like the majority of citizens we did not know of any controversy. We just knew our daughter was ill and becoming worse by the day.

Six months into her illness my wife and I realized something was wrong when the Hartford Children's pediatric infectious disease expert stated "I know Lyme and your daughter doesn't have Lyme disease". He then proceeded to turn away from our daughter and comment "some of these symptoms are" and then twirl his right index finger around his right temple. It was after this appointment that we started to do extensive research on Lyme and tick borne diseases, take our daughter to Boston Children's and eventually have a test done that showed the "presence" of the Lyme bacteria.

I don't want you to think our situation is an isolated case. I've met the parents of two other children who had the same diagnosis and treatment from the Hartford Children's pediatric infectious disease specialist. Chronic Fatigue from a streptococcal infection and she will be better in 6 months. God only knows how many patients he has lost to follow up treatment.

The controversy starts back in the 1980s and covers the time a tick is attached to transmit the pathogens, to the diagnosis, treatment and persistence of infection.

I will highlight one area of the diagnosis to try and illustrate part of the issue.

The diagnosis of Lyme disease is difficult in the sense the bacteria is difficult to culture so "other" methods have been used to help medical professionals.

In 1982 Dr. Burgdorfer isolated the borrelia bacteria in the mid guts of Ixodes ticks. In 1986 Dr. Alan Steere developed the Centers for Disease Control criteria using symptoms and what is known as the Western Blot. The Western Blot is a measure of specific anti bodies against the Lyme borrelia. In 1986 if one had symptoms and had one reactive band it was considered indicative of an underlying borrelia infection¹. However, by 1993 Dr. Steere and the CDC felt Lyme disease was being over diagnosed and over treated². In 1994 at what is known as the

¹ Craft, Fischer, Shimamoto, Steere, Antigens of Borrelia burgdorferi Recognized during Lyme Disease

² Sigal LH. Am J Med. 1990;88:577-581; Steere AC, et al. JAMA. 1993;269:1812-1816

Dearborn conference the CDC established “surveillance” criteria based upon research published by Dr. Steere and Dr. Dressler³.

A summary of this surveillance criteria is either a patient from an endemic area having an erythema migrans “EM” rash, culture, or symptoms with a “positive” Elisa screening test, followed up by a positive Western Blot test⁴. After Dr. Steere’s 1993 paper on the over diagnosis and over treatment this just added to the confusion and developing controversy.

At the time those in the medical community pointed out the Elisa is insensitive⁵ but be positive by the Western Blot (over a 35% false negative rate).

The Western Blot was also controversial in three ways. One, it excluded two Lyme borrelia specific bands, 31-kDa and 34-kDa. It was speculated the vaccine being developed at the time targeted the underlying Lyme borrelia protein and anyone taking the vaccine would be reactive to these two bands. Two, to be considered positive, the serum was required to react with at least 5 of 10 scored bands on the IgG assay and with 2 of 3 scored bands on the IgM assay. Three, it included bands not specific to spirochete bacteria.

Our daughter never tested positive on the Elisa and failed 2 Western Blots based upon the standard criteria. We never knew the band readings. If the physician does not request the band readings in advance they are typically not provided. The physician only receives a positive or negative reading. On the 3rd Western Blot while she was not positive via the CDC she was positive on 2 bands, one specific to the Lyme borrelia and had two indeterminate bands, an antibody reaction just not high enough to be considered positive.

The Infectious Disease Society of America established Lyme disease treatment guidelines in 2000 and based the diagnosis on the 1994 Dearborn standard. The IDSA requires its members to strict adherence to this standard. The standard was updated in 2006 with an independent IDSA committee confirming the process and procedures used by the Lyme committee of the IDSA in 2010.

The Elisa test is easy to use but was updated to the current Elisa C6 peptide in 2000 and the CDC evaluated the Dearborn standard in 2008. Dr. Steere confirmed the standard he co-wrote and had approved at the Dearborn conference in 1994. His conclusion is that the two tier approach using the Elisa C6 peptide and Western Blot is over 95% effective.⁶

I recognize the Lyme research community is small but having one who establishes the criteria be the one to validate it seems to be a conflict of interest. At least it is under my professional standards.

³ MMWR Morb Mortal Weekly Rep. 1995;44:590–591

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⁵ JOCM, Feb. 1996, p. 237–240

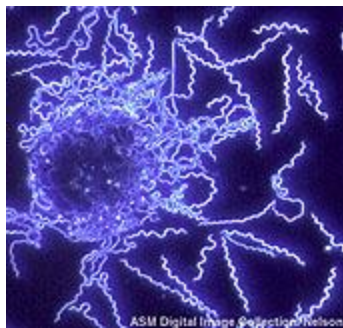
⁶ Steere AC, et al. Clin Infect Dis. 2008;47:188 195

The medical community does not read all the detail of the research papers. They follow what they've been taught, read the guidelines and rely on the experts who have developed them. They may read the underlying references and conclusions but it is rare to find physicians with the time to then read the detail research findings to determine if they support the conclusions.

It's amazing there is a controversy to this insidious disease and I'm afraid the Department of Public Health leading this effort will only make a bad situation worse. As we have seen with last year's General Assembly bill they are against this and I can only see them reinforcing current policy. The prevailing opinion in the medical community is "the last thing we need is a lot more people out there with a misdiagnosis of Lyme disease". The CDC and IDSA position is they do not want to over diagnose and over treat tick borne diseases.

We learned about the controversy to this insidious disease the hard way and our unfortunate experiences are not unique.

Thank you for your time. Below is a dark field imagery of the borrelia spirochete.



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